Informed, Empowered, and Heard: AI and Retrieval-Augmented Generation as Tools for Equitable Patient Information in Oncology

Lars Münter
Nordic Wellbeing Academy, Copenhagen, Denmark | lars@wellbeingacademy.dk

Evangeli Bista
Co-founder Kapa3, libista@kapa3.gr

Maria Lavdaniti
International Hellenic University, Greece, maria_lavdaniti@yahoo.gr

Christos Frantzidis
School of Computer Science, University of Lincoln, UK, cfrantzidis@lincoln.ac.uk

Abstract - Cancer diagnosis confronts patients with an immediate and urgent need for reliable, comprehensible, and personalised information. Yet across Europe, and acutely in Greece, access to high-quality oncology information remains profoundly unequal, shaped by geography, language, socioeconomic status, digital literacy, and the time constraints of overstretched healthcare systems. This paper examines how artificial intelligence (AI), and specifically Retrieval-Augmented Generation (RAG) architectures, can address this inequity by delivering dynamically personalised, evidence-grounded patient information at scale - built by patients and for patient needs, not for hospital workflows. Beyond the technical dimension, the paper argues that the true transformative potential of AI in oncology communication lies not in replacing the human relationship between patients, informal carers, and medical professionals, but in strengthening it to create synergies of collaboration. When patients arrive at clinical encounters better informed, their capacity for shared decision-making is enhanced, their autonomy is respected, and the therapeutic alliance is deepened. The paper additionally draws on neuroscientific evidence on the cognitive burden imposed by cancer diagnosis, arguing that information systems must be designed for the compromised cognitive state of their recipients, not for the idealised attentive reader. Drawing on the Greek oncology context as a specific case within the broader European landscape, and grounding the analysis in established frameworks for patient rights, health literacy, and co-design, this paper presents a principled framework for deploying AI-RAG systems in cancer care in ways that prioritise equity, empowerment, and trust.

Keywords - Retrieval-Augmented Generation; Cancer Patient Information; Health Equity; Patient Empowerment; Patient Rights; Oncology; Digital Health; Greece; Artificial Intelligence

I. I. Introduction

A cancer diagnosis is among the most disorienting experiences a person can face. In the hours, days, and weeks that follow, patients and their families are confronted with a torrent of medical terminology, treatment options, prognosis discussions, and administrative processes - often at a moment of profound psychological vulnerability. Neuroscientific research consistently demonstrates that acute psychological stress of the kind triggered by a serious diagnosis impairs working memory, attentional capacity, and information encoding [2]. The cognitive architecture through which a patient must process a cancer diagnosis is therefore not neutral ground: it is a system under strain, and information designed without accounting for this strain will systematically fail the people who need it most. The quality of information available during this period nonetheless has well-documented consequences for treatment adherence, psychosocial outcomes, and the effectiveness of shared decision-making [1].

Across Europe, access to that information is not equal. In Greece, structural features of the health system compound this inequity: significant urban-rural disparities in oncology service availability, a high proportion of patients navigating the system without professional advocacy support, and persistent gaps in patient-facing communication resources in accessible Greek-language formats [2]. These are not marginal concerns. Greece has one of the highest rates of cancer mortality in Southern Europe, and patient-reported experience data consistently identify information deficits as a primary source of distress and disempowerment.

This paper proposes that AI-powered Retrieval-Augmented Generation (RAG) systems represent a significant opportunity to address these deficits - provided they are designed, deployed, and governed with inclusion, equity, and patient rights at their core.

II. II. What RAG Brings to Oncology Patient Information

Retrieval-Augmented Generation is an AI architecture that combines the generative fluency of large language models with real-time retrieval from curated, verified knowledge bases. Unlike purely generative AI, which draws on patterns in training data and may

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produce plausible but inaccurate responses, RAG systems ground their outputs in specific retrieved documents - clinical guidelines, validated patient information leaflets, regulatory approvals, and peer-reviewed literature - before generating a response [3].

In the oncology context, this architecture offers particular advantages. A cancer patient asking about the side effects of a specific chemotherapy protocol, the eligibility criteria for a clinical trial, or the process for accessing second opinions within the Greek National Health System (ESY) needs answers that are accurate, current, and appropriate to their specific situation. RAG systems can be configured to retrieve from national treatment guidelines (such as those published by the Hellenic Society of Medical Oncology), European clinical guidelines (ESMO, EORTC), and verified patient information resources, then generate responses calibrated to the patient's stated health literacy level, preferred language, and specific clinical context.

Critically, RAG systems can be designed to be transparent about their sources, enabling patients and clinicians to verify the provenance of information - a feature that directly supports informed consent processes and the patient's right to know under both Greek law (Law 2071/1992) and the European Charter of Patients' Rights.

A foundational design principle distinguishing patient-centred RAG from conventional health IT is the direction of the design process itself. Most clinical information systems are built for hospital workflows first, with patient-facing communication treated as a downstream output. AI-RAG systems for oncology patient information must invert this logic: they should be built by patients and for patient needs, with clinical utility as a welcome consequence rather than the primary driver. This distinction determines which questions the system is trained to answer well, which languages and literacy levels it prioritises, and whose definition of useful information shapes its knowledge base.

III. III. Designing for the Distressed Mind: Cognitive Burden in Oncology Information

The moment at which cancer patients most urgently need high-quality information is precisely the moment at which their capacity to receive it is most diminished. Diagnosis and early treatment phases are associated with elevated cortisol levels, disrupted sleep architecture, and sustained activation of stress-response systems that directly compromise the prefrontal cognitive functions - working memory, executive attention, and semantic processing - on which information comprehension depends [2]. This is not a marginal concern for a subset of patients with pre-existing vulnerabilities; it is the normative cognitive condition of a person navigating a cancer diagnosis.

Conventional patient information materials - leaflets, discharge summaries, online portals - are typically designed for a reader with stable attentional resources, sufficient health literacy, and the time and psychological space to engage deliberately with complex content. The cancer patient receiving a treatment plan or a prognosis discussion meets none of these conditions. AI-RAG systems designed with cognitive burden in mind can respond to this reality in ways that static materials cannot: they can adjust response length and complexity dynamically based on interaction signals, offer the same information in multiple modalities (text, audio, simplified summary), enable patients to return to information at a moment of their own choosing rather than the clinician's schedule, and present content in smaller, retrievable units that respect the limits of a stress-impaired working memory.

This cognitive dimension also has direct implications for equity. Patients with lower health literacy, fewer social support resources, or greater socioeconomic stress face compounded cognitive load: they carry the burden of the diagnosis alongside the additional effort of navigating an unfamiliar system in conditions of material insecurity. Information systems that fail to account for cognitive burden will disproportionately fail these patients. Designing for the distressed mind is therefore not a specialist accommodation; it is the foundation of equitable information design.

IV. IV. The Equity Imperative: Greece and the European Context

The distribution of health information in oncology reproduces and often amplifies existing social inequalities. Patients in Athens or Thessaloniki with tertiary education and digital fluency navigate a fundamentally different information environment than patients in rural Epirus or the Aegean islands, or patients whose first language is Albanian, Romani, or Bulgarian [4]. The experience of Greek cancer patient advocacy organisations confirms this picture: patients from underserved communities frequently present to support services not only with unmet clinical needs but with fundamental gaps in their understanding of their diagnosis, their treatment options, and their rights within the system - gaps that earlier, more accessible information could have addressed. The consequences of this inequity are not merely experiential; they are clinical. Information-poor patients make less-informed treatment decisions, experience higher rates of treatment-related anxiety, and are less likely to participate in clinical trials or access supportive care services they are entitled to.

AI-RAG systems, if designed with equity as a primary design constraint, can begin to address this landscape. Multilingual interfaces can serve Greece's substantial migrant population. Adjustable complexity settings can serve patients across the full range of health literacy. Offline-capable or low-bandwidth versions can reach patients in areas with limited connectivity. Voice-based interfaces can serve patients with visual impairments or low written literacy. None of these features are technically complex; they are, however, design choices that require explicit commitment to equity as a value, not an afterthought.

At the European level, the European Health Data Space (EHDS) and the EU AI Act together create both an opportunity and a framework for ensuring that AI systems deployed in healthcare meet minimum standards of equity, transparency, and non-discrimination. Greece, as an EU member state, is positioned to develop RAG-based patient information systems that are compliant with these frameworks while addressing nationally specific needs.

V. V. Empowerment, Patient Rights, and the 40-20-40 Architecture

Patient empowerment in oncology is not simply a matter of providing more information. It requires providing the right information, at the right moment, in a form that the patient can act upon. The 40-20-40 model - which devotes substantial effort to understanding patient expectations before any information intervention and to supporting action after it - provides a design framework for AI-RAG patient information systems that applies at two levels [5]. The first is the level of system design: the RAG knowledge base itself, the questions it is optimised to answer, and the interaction patterns it supports should be co-designed with patients and informal carers, not derived solely from clinical guidelines or administrative priorities. The second is the level of individual use: each patient's engagement with the system should follow the prologue-intervention-epilogue rhythm, beginning with expectation-setting and ending with supported action.

In practice, this means that an effective AI-RAG system in oncology should do more than answer queries. It should engage patients in a dialogue about what they most want to understand, surface concerns that patients may not know how to articulate, and actively support them in preparing for clinical consultations. Features such as 'consultation preparation guides' generated from a patient's prior queries, question prompts aligned with upcoming appointments, and post-consultation summaries that consolidate what was discussed all represent applications of the prologue-epilogue logic to the information support context.

Patient rights frameworks - including the right to informed consent, the right to a second opinion, the right to access one's own medical record, and the right to refuse treatment - are frequently poorly understood by patients who are most vulnerable and most in need of their protection. AI-RAG systems can embed patient rights information directly into contextually relevant interactions: a patient asking about a proposed surgery can receive simultaneously the clinical explanation and a plain-language account of their consent rights.

VI. VI. Strengthening the Triad: Patients, Carers, and Clinicians in an Age of AI

The true transformative potential of AI in oncology communication does not lie in information delivery alone. It lies in the synergies of collaboration it can generate between patients, informal carers, and medical professionals - a triad that, when functioning well, is among the most powerful determinants of cancer outcomes and quality of life. A central risk in the deployment of AI for patient information is therefore that it is perceived - by patients or by clinicians - as a substitute for human communication rather than a catalyst for richer human connection. This perception, where it takes hold, undermines trust in both the AI system and in the clinical relationship it was intended to strengthen.

The evidence from health communication research is unambiguous: the quality of the relationship between patients, informal carers, and medical professionals is among the strongest determinants of treatment outcomes, quality of life, and patient-reported experience in oncology [6]. AI-RAG systems should be designed explicitly to strengthen this relationship, not to bypass it. This means, concretely, that AI-generated information should always be positioned as preparation for, or follow-up from, clinical conversations - never as a replacement for them.

For informal carers - whose role in the Greek oncology context is particularly significant given the relative underdevelopment of professional home care services - AI-RAG systems offer specific value. Carers frequently carry information burdens that are as heavy as those of patients, with less institutional support and, importantly, with their own form of secondary cognitive stress: the sustained vigilance, emotional labour, and anticipatory anxiety of caring for a seriously ill person imposes cognitive costs that are well-documented in the caregiving literature [6]. Information systems designed for the carer-patient dyad must account for this dual cognitive burden. Systems designed to serve the carer-patient dyad, providing coordinated information that supports both parties and facilitates their joint preparation for clinical encounters, represent a meaningfully different design ambition than systems focused solely on the patient.

For healthcare professionals, trustworthy AI-RAG systems can reduce the time spent on basic information provision, freeing clinical encounters for the nuanced, relational, and decision-focused conversations that patients most value and that AI cannot replicate. Oncologists and nurses who trust that their patients arrive at consultations with a reliable informational foundation are better positioned to engage in genuine shared decision-making.

VII. VII. Conclusion

Cancer patients in Greece and across Europe deserve access to information that is accurate, personalised, accessible, and rights-respecting - regardless of where they live, what language they speak, or what socioeconomic resources they can bring to their care. AI-RAG architectures, designed with equity and empowerment as primary design constraints, represent a realistic and scalable pathway toward this goal.

The key insight of this paper is that the value of AI in oncology patient information is not primarily technical.

It is relational. Systems that strengthen the bond between patients, informal carers, and medical professionals - that arrive at clinical encounters better prepared, more empowered, and more confident in their rights - will generate outcomes that no purely clinical intervention can produce. Greece, with its specific challenges of geographic disparity and system capacity, and with its membership of a European regulatory framework increasingly oriented toward AI governance and health data equity, is well-positioned to develop and share models that the continent as a whole can learn from.

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IX. References

[1] Faller H. et al., "Effects of psycho-oncologic interventions on emotional distress and quality of life in adult patients with cancer," Journal of Clinical Oncology, 31(6), 2013.

[2] Lupien S.J. et al., "Effects of stress throughout the lifespan on the brain, behaviour and cognition," Nature Reviews Neuroscience, 10(6), 2009.

[3] Hellenic Society of Medical Oncology (HESMO), "Annual Report on Cancer Burden and Care Access in Greece," 2023.

[4] Lewis P. et al., "Retrieval-Augmented Generation for Knowledge-Intensive NLP Tasks," Advances in Neural Information Processing Systems, 2020.

[5] Sørensen K. et al., "Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU)," European Journal of Public Health, 25(6), 2015.

[6] Münter L. et al., "Transforming health systems with design health literacy: Presenting the 40-20-40 model for digital development," Computer Methods and Programs in Biomedicine Update, Vol. 4, 100122, 2023.

[7] Epstein R.M. & Street R.L., "Patient-centered communication in cancer care: Promoting healing and reducing suffering," National Cancer Institute, NIH Publication No. 07-6225, Bethesda, MD, 2007.

[8] European Commission, "European Health Data Space Regulation," 2022.

[9] Bevans M. & Sternberg E.M., "Caregiving burden, stress, and health effects among family caregivers of adult cancer patients," JAMA, 307(4), 2012.

[10] Active Citizenship Network, "European Charter of Patients' Rights," Rome, 2002.